AN ANALYSIS OF MOVEMENT FROM STATE OPERATED DEVELOPMENTAL CENTERS IN ILLINOIS

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September 2010





Prepared for the Illinois Department of Human Services
Division of Developmental Disabilities

ACKNOWLEDGEMENTS

Many thanks to Jayma Tucker, Assistant Chief, Bureau of Quality Management, DHS/DDD, for coordinating the gathering of the information used for this analysis. Special thanks also to the staff at each of the State Operated Developmental Centers for assisting in gathering this information for submission. Gratitude is also due to Abigail Schindler, MS for assistance with report formatting. Finally, we are grateful to the Illinois Department of Human Services, Division of Developmental Disabilities for funding this project.

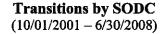
Preferred citation: Lulinski Norris, A., Rizzolo, M.C. & Heller, T. (2010). An Analysis of Movement from State Operated Developmental Centers in Illinois. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

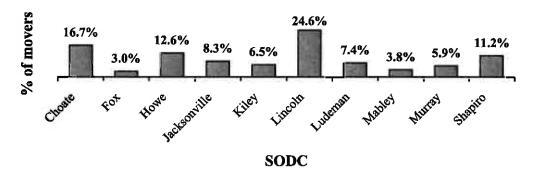
The Department of Human Services, Division of Developmental Disabilities contracted the Institute on Disability and Human Development at the University of Illinois at Chicago to conduct an analysis of State Operated Developmental Centers (SODCs) census reduction data between October 1, 2001, and June 30, 2008. Data were collected and analyzed to determine characteristics and outcomes of persons transitioning out of SODCs in Illinois. Prior to this project, a study investigating transitions across all Illinois SODCs over an extended period of time has not been completed.

FINDINGS

QUESTION 1: How many individuals transitioned out of Illinois SODCs since the initiation of closure of Lincoln Developmental Center on October 1, 2001?

• During the reporting period, October 1, 2001 through June 30, 2008, there was a total census reduction of 1,613 individuals in the Illinois SODC system. Of the 1,613 individuals, 133 died while residing in an SODC, resulting in 1,480 individuals transitioning to other placements. The SODC with the highest number of transitions was Lincoln, while Fox had the least.





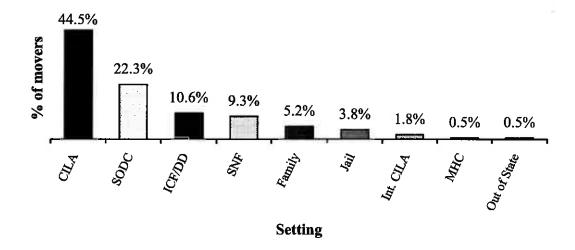
QUESTION 2: What are the characteristics of those who transitioned out of SODCs in Illinois?

- The average age was 47.2 years old; the youngest was 16 and the oldest was 95.
- The majority (66.8%) were men.
- Nearly half (47.6%) had a psychiatric diagnosis at transition
- 44.7% had a diagnosis of profound intellectual disability, while 16.6%, 16.2% and 20.7% had a severe, moderate, or mild level of intellectual disability, respectively.
- 7.2% had a diagnosis on the autism spectrum.
- 76.4% had a court appointed guardian (including private and public guardians).
- The average ICAP Adaptive Behavior score was 53.5 months (approximately 4.5 years) with a range of 1-336 months.
- The average ICAP Service Level Score was 45.3 (range 1-98).
- The average Health Risk Screening Tool care level was 2.46 (range 1-6).

QUESTION 3: To what type of residential settings did individuals transition?

- The majority (51.4%) moved from an SODC into a community setting [i.e., 24 hour Community Integrated Living Arrangements (CILA), intermittent CILA, Family Home], while 46.6% moved from an the SODC into another congregate setting [i.e., another SODC, Skilled Nursing Facility (SNF), Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD), State Operated Mental Health Center (MHC), or jail].
- 76.5% of persons that left Lincoln transitioned into another SODC.

Transitions by Placement Setting (10/01/2001 – 6/30/2008)



QUESTION 4: To what extent did individuals remain in their transition setting?

- Half (50.4%) of the individuals remained in their transition setting. Of this group, 9.8% received some type of Technical Assistance (TA). Nearly three quarters (74%) of the TA was for behavioral issues.
- SODCs did not have information on the current status of 19.9% of the individuals who transitioned out.
- 11.1% died.
- 10.4% returned to an SODC.
- 6.3% changed residential providers.

QUESTION 5: What are the characteristics of the persons who returned to an SODC after transition as compared to those who remained in their transition placement?

- 154 individuals returned to an SODC after transition.
- 72.7% (n=112) returned due to behavioral reasons.
- 28.6% received technical assistance, of which 68% was for behavioral issues.
- Of those who transitioned to CILA, only 43.8% remained in their CILA placement after receiving technical assistance.
- As compared to those returning to an SODC, persons remaining in their transition placement:
 - Had lower IQs;
 - Had lower ICAP Adaptive Behavior scores;
 - Had lower ICAP Service Level scores;
 - Had a longer length of previous stay at an SODC; and
 - Were older.
- Presence of psychiatric diagnosis was similar but not statistically significant for both groups – 47.8% for those remaining in their transition placement and 52.6% for those returning to an SODC.

QUESTION 6: How do characteristics of persons that transitioned compare across residential settings?

- Overall, there was a significant difference with respect to HRST scores, ICAP Behavioral and Service Level scores, IQ, and length of stay at SODC between groups.
 - Persons that moved from an SODC into a family member's house or into the corrections system were typically younger, had a higher IQ, as well as higher ICAP Adaptive Behavior scores and Service Level Score. They tended to have a lower Health Risk Screening Tool (HSRT) scores and a

- shorter length of stay in the SODC; however, they were as likely as other transitioning individuals to have a psychiatric diagnosis.
- Persons who moved into a nursing home tended to be older, have a lower IQ, as well as lower ICAP Adaptive Behavior scores and Service Level scores than individuals who moved to other settings. They tended to have a higher health risk and were less likely to have a psychiatric diagnosis.

QUESTION 7: What are the characteristics of the individuals who have died since transition?

During the study period, the only significant difference between individuals who
died in an SODC and those individuals who died post-transition was with respect
to HRST scores and length of stay. Individuals dying post-transition had a
significantly higher health risk as well as a significantly longer previous stay at an
SODC as compared to their counterparts.

THEMES

In addition to answers to the initial research questions, six themes emerged from the data:

<u>Theme 1</u>: During periods of SODC closure, individuals living in SODCs were less likely to transfer to community settings.

<u>Theme 2</u>: The majority (39%) of post-transition deaths occurred in Skilled Nursing Facilities.

<u>Theme 3:</u> As evidenced by the absence of transition data at the SODC level, the utility of post-transition outcome data could be strengthened through sharing and coordination at varying Department levels.

<u>Theme 4:</u> The most frequent reason for return to SODCs across all centers was due to behavioral issues, warranting analysis of the type, severity and duration of the particular behaviors contributing to return as well as examination of the accessibility, delivery, and effectiveness of related community-based behavioral supports in Illinois.

<u>Theme 5</u>: Individuals who were transferred to jail settings had a high likelihood of failed community placement after release from jail, suggesting that existing community-based supports may not be adequate for this population.

<u>Theme 6</u>: Only 28% of individuals returning to an SODC post-transition received documented technical assistance, warranting further analysis to inform future transition policy.

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INTRODUCTION

The United States has a long tradition of providing services to people with intellectual and/or developmental disabilities (I/DD) in large public congregate settings. Since peaking in 1967 (Scott, Lakin, & Larson, 2008), deinstitutionalization has occurred at an average annual rate of 4% nation-wide, resulting in the closing of 140 public institutions in 40 states (Braddock, Hemp & Rizzolo, 2008). Although it has shuttered four State Operated Developmental Centers (SODCs) since 1982, Illinois remains among the states with the highest rates of institutionalization of persons with I/DD in the country. During the time of the reporting period, Illinois had nine active SODCs, ranking it sixth nationally in utilization of public/private institutions (Braddock, Hemp, & Rizzolo, 2008).

Numerous studies have been completed examining deinstitutionalization outcomes for individuals and have focused on movement from institutions to community-based settings (see Kim, Larson, and Lakin, 1999; and Heller, Schindler & Rizzolo, 2008). Similar studies have been conducted in Illinois to determine outcomes for individuals leaving SODCs (Braddock, Heller & Zashin, 1984; Heller, Factor & Braddock, 1986; Fujiura, Fitzsimons-Cova & Bruhn, 2002).

In the spirit of continued monitoring of outcomes for individuals transitioning out of Illinois SODCs, the Department of Human Services' Division of Developmental Disabilities contracted the Institute on Disability and Human Development at the University of Illinois at Chicago to examine outcomes for individuals transitioning out of SODCs between October 1, 2001, and June 30, 2008. Seeking information on where individuals transitioned to and the success rate of such placements, the researchers focused on the following seven questions:

- 1. How many individuals transitioned out of Illinois SODCs since the initiation of the closure of the Lincoln Developmental Center on October 1, 2001?
- 2. What are the characteristics of those who transitioned out of SODCs in Illinois?

- 3. To what type of residential settings did individuals transition?
- 4. To what extent did individuals remain in the residential setting to which they were transitioned?
- 5. What are the characteristics of the persons who returned to an SODC after transition as compared to those who remained in their transition placement?
- 6. How do characteristics of persons that transitioned compare across residential settings?
- 7. What are the characteristics of the individuals who have died since transition during the reporting period?

It is anticipated that the information gathered as a result of this project will provide insight into the factors contributing to successful transitions from SODCs to alternative placements and may assist in future transition planning at not only the individual and center level, but at the state policy level as well.

METHODS

The current project investigated outcomes of individuals who moved out of Illinois' State Operated Developmental Centers (SODCs) between October 1, 2001, and June 30, 2008. This time period reflects all activity since the initiation of the closing of Lincoln Developmental Center.

Information was collected from the following domains:

- 1) demographic information including diagnoses;
- 2) type of setting the individual transitioned to;
- 3) status of individual's residential placement as of June 20, 2008;
- 4) reason(s) for changes in individual's residential placement;
- 5) type of technical assistance provided (if any).

Data was gathered by the Illinois Department of Human Services from each of the SODCs, de-identified, and submitted to the researcher (see Appendix L for form used in data collection). Data gathered included the following information as of June 30, 2008:

- 1) Gender
- 2) Month and year of birth
- 3) Most recent date of admission to SODC
- 4) SODC individual transitioned from
- 5) Date transitioned from SODC
- 6) Health Risk Screening Tool level
- 7) ICAP Adaptive Behavior Score
- 8) ICAP Service Level Score
- 9) IQ at time of transition
- 10) Presence and level of intellectual disability
- 11) Presence of autism spectrum disorder and diagnosis
- 12) Medical diagnoses using ICD-10 classifications
- 13) Presence and type of psychiatric diagnosis
- 14) Name of residential provider to which the individual transitioned

- 15) Type of residential setting transitioned to
- 16) Number of residents residing in transition setting
- 17) Guardianship status
- 18) Current type of residence
- 19) Whether or not individual returned to an SODC and reason
- 20) Provision and type of technical assistance post-transition

Data was coded and then analyzed using SPSS 16.0. This report presents analysis which includes descriptive information and basic comparisons between transition groups.

QUESTION 1: How many individuals were transitioned out of Illinois SODCs since the initiation of closure of the Lincoln Developmental Center on October 1, 2001?

During the reporting period, October 1, 2001 through June 30, 2008, there was a total census reduction of 1,613 individuals from all nine Illinois SODCs. One hundred and thirty three (8.2%) of those individuals died while residing in an SODC. These deaths were not used in the statistical analysis of outcomes, although they were considered separately at the end of the report as well as in the Appendices.

Table 1. Total Transitions out of all SODCs
Between 10/01/2001 and 6/30/2008

SODC	#	%
Choate	248	16.8
Fox	44	3.0
Howe	186	12.6
Jacksonville	123	8.3
Kiley	97	6.6
Lincoln	363	24.5
Ludeman	109	7.4
Mabley	56	3.8
Murray	88	5.9
Shapiro	166	11.2
Total	1480	*

^{*} due to rounding, percentage does not equal 100

The largest number of transitions occurred at Lincoln Developmental Center due to the initiation of its closure on October 1, 2001. In total, 363 individuals transitioned out of Lincoln, comprising 24.5% of all transitions in the study sample. The second largest group was from Choate Developmental Center where 248 (16.8%) of all transitions occurred. Howe Developmental Center transitioned 186 (12.6%) individuals, while Shapiro transitioned 166 (11.2%). Jacksonville and Ludeman each transitioned over 100 individuals, 123 (8.3%) and 109 (7.4%) respectively. Kiley transitions accounted for 97

(6.6%), while Murray transitioned 88 people (5.9%). Mabley and Fox transitioned the smallest number of people during the study period, totaling 56 (3.8%) and 44 (3.0%), respectively.

Table 2. SODC Transitions by Fiscal Year (10/01/2001 – 6/30/2008)

SODC	FY02	FY03	FY04	FY05	FY06	FY07	FY08	Total
Choate	22	43	39	52	27	37	28	248
Fox	5	9	0	11	5	5	9	44
Howe	13	37	28	20	19	28	41	186
Jacksonville	10	12	19	18	9	28	27	123
Kiley	6	18	10	16	13	23	11	97
Lincoln	122	241	0	0	0	0	0	363
Ludeman	7	17	6	19	9	35	16	109
Mabley	6	12	9	8	15	2	4	56
Murray	5	5	14	16	5	20	23	88
Shapiro	15	25	21	23	27	20	35	166
Total	211	419	146	183	129	198	194	1480
% of Total	14.3%	28.3%	9.9%	12.4%	8.7%	13.4%	13.1%	*

^{*} due to rounding, percentage does not equal 100

Overall, FY2003 saw the greatest number of transitions out of SODCs accounting for 28.3%; followed by FY2002 with 14.3%; FY2007 with 13.4%; FY2008 with 13.1%, and FY2005 with 12.4%. FY 2006 saw the lowest number with 8.7% of all transitions occurring that year.

Figure 1. Transitions by Fiscal Year (10/01/2001 - 6/30/2008)

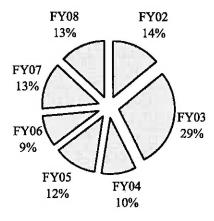


Table 3. Demographics of Those Transitioned Between 10/01/2001 and 6/30/2008

	#	%
Gender		
Male	989	66.8%
Female	487	32.9%
Missing	4	.03%
Psychiatric Diagnosis		
Yes	705	47.6%
No	775	52.3%
Level of ID		
Mild	306	20.7%
Moderate	240	16.2%
Severe	246	16.6%
Profound	663	44.8%
N/A	16	1.1%
Not specified	8	0.5%
Missing	1	0.1%
ASD Diagnosis		
No	1374	92.8%
Yes	108	7.3%
Autism	70	65%
PDD, NOS	38	35%
Guardianship status		
Legally competent	164	11.1%
Private guardian – family member	655	44.3%
Private guardian – non family member	35	2.4%
Public Guardian	440	29.7%
Unknown/not listed	186	12.6%

Age

Of the 1,480 individuals who transitioned out of the 10 Illinois SODCs during the study period, the youngest was 16 and the oldest was 95 (mean = 46.78, sd = 13.995).

Length of stay

Average length of stay for the 1,480 individuals at an Illinois SODC was 13.8 years with a range from less than one year to 77 years (sd=13.6).

Psychiatric Diagnosis

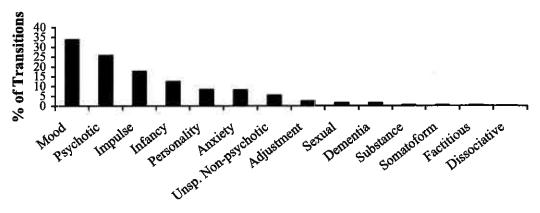
Of the 1,480 individuals transitioned during the study period, 705 (47.6%) had a psychiatric diagnosis. Of the 705, 134 (19%) had more than one psychiatric diagnosis. One-third of those with a psychiatric diagnosis (33.9%, n = 239) had a mood disorder; one-fourth (25.8%, n = 182) had a diagnosed psychotic disorder; 125 (17.7%) had an impulse control disorder; 88 (12.5%) had a diagnosis of a disorder usually first identified in infancy, childhood, or adolescence; 59 (8.4%) had a personality disorder; 58 (8.2%) had an anxiety disorder; 39 (5.5%) had an unspecified non-psychotic disorder; 18 (2.5%) had an adjustment disorder; 10 (1.4%) had a sexual and/or gender identity disorder; 10 (1.4%) had a delirium or dementia diagnosis; 3 (.04%) had a substance related disorder; 2 (0.3%); 2 (0.3%) had a factitious disorder; and one individual (0.1%) had a diagnosis of a dissociative disorder.

Table 4. Types of Psychiatric Diagnoses of Those Transitioning Out of SODCs with Psychiatric Diagnoses Between 10/01/2001 and 6/30/2008

Psychiatric Diagnosis*	#	%
Mood disorder	239	33.9
Psychotic disorder	182	25.8
Impulse disorder	125	17.7
Disorders usually first identified in infancy childhood or adolescence	88	12.5
Personality disorder	59	8.4
Anxiety disorder	58	8.2
Unspecified, non-psychotic	39	5.5
Adjustment disorder	18	2.5
Sexual and/or gender identity disorder	10	1.4
Delirium or dementia	10	1.4
Substance related disorder	3	0.42
Somatoform disorder	2	0.28
Factitious disorder	2	0.28
Dissociative disorder	1	0.14

^{*}Some individuals had more than one psychiatric diagnosis

Figure 2. Psychiatric Diagnoses of Those Transitioned Between 10/01/2001 and 6/30/2008

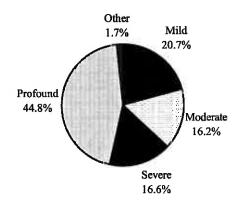


Psychiatric Diagnosis

Level of Intellectual Disability

Of the 1,480 individuals transitioning out of an SODC during the study period, 1,455 (98.3%) had a specific diagnosis of intellectual disability (ID). Of those 1,455 individuals with a diagnosis of intellectual disability, 306 (21.0%) had a diagnosis of mild intellectual disability, 240 (16.5%) moderate, 246 (16.9%) severe, and 663 (45.6%) profound. The nearly two percent (1.8%), represented in the pie chart as "other," were either missing (n=1), not specified (n=8), or not diagnosed with intellectual disability (n=16).

Figure 3 Levels of ID of Those Transitioned Between 10/01/2001 and 6/30/2008



Autism Spectrum Diagnosis

One hundred and eight (7.3%) of the individuals transitioned out of an SODC during the study period had a diagnosis on the autism spectrum. Of the 108 individuals, 70 (65%) had a diagnosis of autism and 38 (35%) had a diagnosis of Pervasive Developmental Disorder, Not Otherwise Specified. None of the individuals had a diagnosis of Asperger's Syndrome.

Inventory for Client and Agency Planning (ICAP) Scores

Adaptive Behavior Score

The ICAP Adaptive Behavior Score measures an individual's level of functioning based on their Adaptive Behavior and indicates the individual's age equivalent score in years and months. It is the average score of four main domains: Motor skills; Social and Communication skills; Personal Living skills; and Community Living skills. These scores are used to categorize individuals by level of functioning in four categories: mild, moderate, severe, and profound (see Table 5).

Table 5. ICAP Adaptive Behavior Level

Level of Functioning	Mental Age Score Ranges (in months)
 Mild	102 - 121 months
Moderate	73 - 101 months
Severe	45 – 72 months
Profound	<45 months

The average Adaptive Behavior Score for all transitioning individuals was 53.5 months (sd = 47), which is equivalent to approximately 4 ½ years and in the severe level of functioning. Sample ICAP Adaptive Behavior Scores ranged from 1 - 336 months (28 years).

Service Level Scores

The ICAP Service Level Score is a combination of adaptive behavior scores and maladaptive behavior scores. ICAP Service Scores range from 0 to 100, and indicate the need for various levels of support, listed in Table 6.

Table 6. ICAP Service Level Scores

Level	Score	Description
Level 1	1-19	Total personal care and intense supervision
Level 2	20-29	Total personal care and intense supervision
Level 3	30-39	Extensive personal care and/or constant supervision
Level 4	40-49	Extensive personal care and/or constant supervision
Level 5	50-59	Regular personal care and/or close supervision
Level 6	60-69	Regular personal care and/or close supervision
Level 7	70-79	Limited personal care and/or regular supervision
Level 8	80-89	Limited personal care and/or regular supervision
Level 9	90+	Infrequent or no assistance for daily living

The range of ICAP Service Level Scores was 1 - 98. The average ICAP Service Level Score was 45.4 (sd = 20.97), which indicates a need for extensive personal care and constant supervision.

HRST Scores

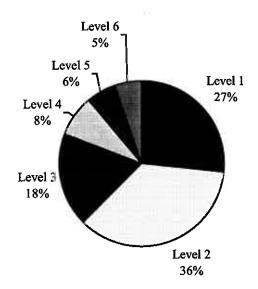
The Health Risk Screening Tool (HRST) was designed to screen for health risks associated with disabilities and is determined by rating an individual's risk and care levels across five domains: functional status, behavior, physiological, safety, and frequency of services. The final HRST score indicates health care levels and degrees of health risk for the individual as indicated in Table 7.

Table 7. Health Care Levels
Health Care Levels

Level 1	Low Risk
Level 2	Low Risk
Level 3	Moderate Risk
Level 4	High Moderate Risk
Level 5	High Risk
Level 6	Highest Risk

The range of HRST scores was 1-6 and the average HRST level was 2.46 (sd = 1.39), which is in the low risk level of care. Over three quarters (81%) of the individuals had HRST scores that were in the low to moderate risk level. Figure 3 illustrates the breakdown of HRST scores for transitioning individuals.

Figure 4. HRST Scores of Those Transitioned Between 10/01/2001 and 6/30/2008



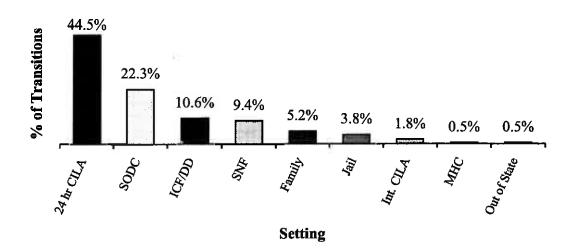


Figure 5. Transitions by Setting Between 10/01/2001 and 6/30/2008

Of the 1,480 people leaving an SODC during the study period, 658 (44.5%) went to live in a Community Integrated Living Arrangement (CILA) in which 24-hour support is provided; 330 (22.3%) transferred to another SODC in Illinois; 157 (10.6%) moved into an Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD); 139 (9.4%) moved into a Skilled Nursing Facility (SNF); 77 (5.2%) went to live with a family member; 56 (3.8%) transferred to a jail; 26 (1.8%) moved into an Intermittent CILA with less than 24-hour supports; 8 (0.5%) transferred to a State Operated Mental Health Center (MHC); 7 (0.5%) moved out of state; 9 (0.6%) moved into another setting; and data is unavailable for 13 (0.9%) of the individuals.

A total of 46.6% of individuals (n = 690) transitioned into another institution. These institutions included: another SODC, ICF/DD, SNF, Mental Health Center, and jail (as data did not distinguish between jail and prison, the term "jail" is used throughout this report). One hundred per cent of those transferred to jail came from Choate's Developmental Disability Forensic Unit. Additionally, 51.4% (n = 761) moved to community settings including 24-hour CILA, intermittent CILA, and to a family member's home.

Table 8. Transitions by SODC & Provider Between 10/01/2001 and 6/30/2008

	Choate Fox	Fox	Howe	Jacksonville	Kiley	Lincoln	Ludeman	Mabley	Murray	Shapiro	Total	%
CILA	48	20	185	73	72	43	63	39	41	74	859	44.5%
Other SODC	21	-	0	7	7	283	S	∞	3	0	330	22.3%
ICE/DD	34	0	0	22	∞	13	23	4	29	24	157	10.6%
SNF	14	19	1	6	6	œ	∞	0	6	62	139	9.4%
Family Member	46	1	0	8	-	5	S	e	5	9	11	5.2%
Jail	99	0	0	0	0	0	0	0	0	0	99	3.8%
Int. CILA	24	0	0	-	0	0	0	-	0	0	26	1.8%
Undocumented	0	æ	0	0	0	10	0	0	0	0	13	%6.0
Other	7	0	0	1	0		S	0	0	0	6	0.6%
State Operated Mental Health Center	т	0	0	4	0	0	0	-	0	0	∞	0.5%
Out of State	0	0	0		3	0	0	0	-	0	7	0.5%
Total	248	4	186	123	97	363	109	56	8	166	1480	*

*Due to rounding, percentages do not equal 100.

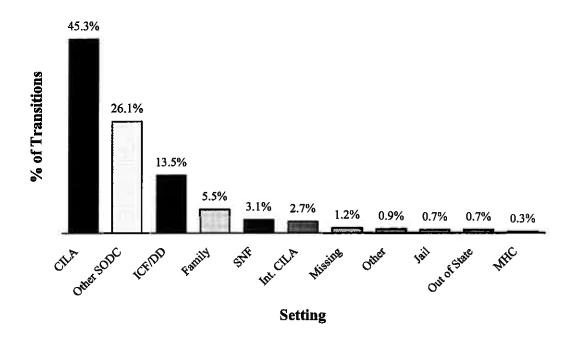
Table 9. Status of Transitioned Individuals as of 6/30/2008

Placement	#	%
Continuous placement (remained with transition provider)	746	50.4
Undocumented	295	19.9
Deceased	164	11.1
Returned to an SODC	154	10.4
Different residence, different provider (non-SODC)	93	6.3
Same provider, different residence	25	1.7
State Operated Mental Health Center	1	.1
Missing	2	.1
Total	1480	*

^{*}Due to rounding, percentages do not equal 100.

Of the 1,480 individuals that moved out of an SODC during the study period, 50.4% (746) remained in the residential placement to which they transitioned as of June 30, 2008; 25 (1.7%) remained with the same provider but had moved into another setting; 93 (6.3%) had changed providers; 154 (10.4%) returned to an SODC; 164 (11.1%) died; 1 (0.1%) transferred to a mental health facility, and, the whereabouts of 295 (19.9%) were undocumented. The unknown current living situation of these individuals may be due to regulations requiring post-transition follow-up only up to one year after transition, meaning that data for persons having moved into a setting other than their initial transition placement was not captured by the SODC from which they moved. The majority (50.4%) of individuals leaving an SODC during the study period remained in their transition placement as of June 30, 2008.





Of the 746 individuals who remained in their transition placement as of June 30, 2008, 338 (45.3%) remained in CILA placement; 195 (26.1%) remained in the SODC to which they were transferred; 101 (13.5%) remained in their ICF/DD placement; 41 (5.5%) remained in their family placement; 23 (3.1%) remained in their Skilled Nursing Facility placement; 20 (2.7%) remained in their Intermittent CILA placement; 9 (1.2%) of those for whom relocation information is missing reportedly remained in their placement; 7 (0.9%) of those for whom 'other' was indicated as their placement remained in such; 5 (0.7%) remained in jail; 5 (0.7%) that moved out of state remained in their out of state placement; and two (0.3%) individuals whom were transferred to a State Operated Mental Health Center remained in that placement.

Question 5: What are the characteristics of the persons who returned to an SODC after transition as compared to those who remained in their transition placement?

Table 10. Comparison of Characteristics of Those Returning to an SODC and Those Remaining in Transition Placement

_	Returning (n = 154)	Remaining (n = 746)	Significance (p value)
Mean Age	42.2	47	p = .000§
Mean IQ	39.9	27.6	p = .000§
Mean ICAP Adaptive Behavior Score (in months)	69.7	50	p = .000§
Mean ICAP Service Level Score	52.4	43.8	p = .000§
HRST	2.32	2.27	p = .657§
Presence of Psychiatric Diagnosis	52.6 %	47.3%	p = .233‡
Mean Length of Previous Stay at SODC in years	8.6	15.2	p = .000§
Provision of Technical Assistance			
Yes No Missing	27.9% 61% 11.0%	9.8% 61.1% 29.1%	p = .000‡
Type of Technical			
Assistance† Medical Behavioral Medical & behavioral Dietary	23% 70% 7% 0%	1% 74% 19% 5%	p = .000‡

[§]Based on an independent samples T-test

[‡] Based on Chi Square test

[†] Due to rounding, numbers do not add up to 100%.

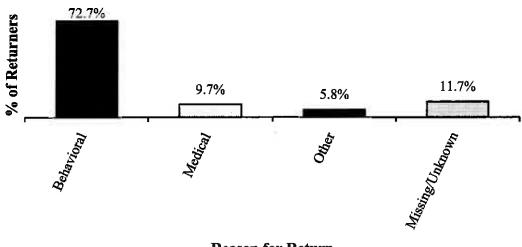
In total, 154 (10.4%) individuals returned to an SODC after transitioning out. Of those 154 individuals, 118 (76.6%) were male and 36 (23.4%) were female with an average age of 42.2 years (sd = 12.99, ranging 17 – 78). Nearly 53% had a psychiatric diagnosis. The average IQ was 39.9 (range 1-91, sd = 21.42). The average ICAP Adaptive Behavior Score was 69.7 (range 3-207, sd = 47.5), average ICAP Service Level Score was 52.4 (range 4-91, sd = 20.29), average HRST was 2.32 (range 1-6, sd = 1.37), average length of stay at prior SODC placement was 8.6 years (range less than one year to 50 years, sd = 10.88). The majority of individuals, (86, or 55.1%) had a private guardian, while 36 (23.1%) had a public guardian, and 23 (14.7%) were legally competent.

For the purposes of this report, technical assistance (TA) is defined as supports offered to individuals transitioning out of an SODC that fall outside of the parameters of routine follow-up. Such routine follow-up is called Direct Linkage and Aftercare (DLA) and is outlined in Illinois Administrative Code, Title 59, Chapter 1, Part 25 entitled Recipient Discharge/Linkage/
Aftercare. Technical assistance is support provided in addition to DLA, and is offered for individuals experiencing behavioral and/or medical concerns for which the service provider requires input from a specific discipline. Technical assistance may include: face-to-face visits by a staff familiar with the individual; observation, evaluation, and provision of recommendations by discipline specific professionals to address identified issues; a focused review of past records, information gathering, information dissemination, training, consultation, and related activities; or a conference call with an interdisciplinary team from the SODC and community provider, as well as Division of Developmental Disability staff. Available information on TA was limited to whether or not it was provided for medical, behavioral, or dietary issues but did not specify how the support was delivered.

Of the 154 individuals that returned to an SODC after having transitioned out of one, 112 (72.7%) returned due to behavioral reasons; 15 (9.7%) due to medical reasons; 9 (5.8%) due to reasons listed as 'other'; and 18 (11.7%) returned for missing or unknown reasons. Of these returning, 28% received technical assistance, 61% did not receive TA, and for the remaining 11%, whether or not they received TA is not documented. Of those returning to the SODC after having received TA, the majority of the TA delivered to these individuals was in response to

behavioral issues (70%, n = 30), 23% (n = 10) medical issues, and 7% (n = 3) a combination of medical and behavioral issues. None of the individuals returning received TA for dietary issues.

Figure 7. Reasons for Return to SODC for Individuals Transitioned Between 10/01/2001 and 6/30/2008



Reason for Return

There were 746 persons remaining in their transition placement on June 30, 2008. Of these 746 individuals, 484 (64.9%) were male and 260 (34.9%) were female while the sex of two (0.3%) individuals was not specified. The average age was 47 (sd = 15.34), average IQ was 27.6 (sd = 20.9), average ICAP Adaptive Behavior Score was 50 (sd = 44.25), average ICAP Service Level Score was 43.8 (sd = 20.43), average HRST was 2.27 (sd = 1.2), average length of stay at prior SODC placement was 15.2 years (sd = 13.25). The majority of individuals, (317, or 42.5%) had a private guardian, while 241 (32.3%) had a public guardian, and 70 (9.4%) were legally competent. One hundred and eighteen individuals (15.8%) did not have guardian status indicated.

Of those individuals remaining in their transition placement, 9.8% received TA, 61.1% did not receive TA, and for the remaining 29.1% it is unknown as to whether they received TA. Of those receiving TA, the majority was for behavioral issues (74%), 1% was for medical issues

only, while 19% was for a combination of medical and behavioral issues, and 4% of individuals received TA for dietary issues.

Persons remaining in their transition placement were significantly older, had a significantly longer previous length of stay at an SODC, had a significantly lower IQ, and significantly lower ICAP Adaptive Behavior and ICAP Service Level scores than those returning to an SODC. There was no significant difference between HRST scores between the two groups. Presence of psychiatric diagnosis was similar between the two groups -47.3% for those remaining and 52.6% for those returning to an SODC, however, this difference was not statistically significant (p = .233).

Question 6: How do characteristics of persons compare across residential settings?

Overall, there was a significant difference between groups with respect to HRST scores, ICAP Behavioral and Service Level scores, IQ, and length of stay at SODC. Transitions to Intermittent CILA were not included in this portion of the analysis due to low incidence of this type of placement.

There was no significant difference with respect to age between those transferring to an SODC, CILA, or ICF/DD. Those transitioning to a 24-hour CILA had a significantly higher ICAP Adaptive Behavior score and Service Level score than all other groups except for those moving in with families or going to jail. In addition, individuals moving to a CILA had a collectively higher IQ as compared to those moving to SODC, ICF/DD or SNF, but significantly lower than that of those moving into family homes or into jail. This group had the highest occurrence of psychiatric diagnosis at 52.2%.

Table 11. Comparison of Characteristics of Individuals Transitioning By Residential Setting Between 10/01/2001 and 6/30/2008

	Overall (n = 1480)	CILA (n = 658)	SODC (n = 330)	ICF/DD (n = 157)	SNF (n = 139)	Family (n = 77)	Jail (n=54)
Mean Age	46.8	47.1	47.6	46.8	57.8	35.5	30.3
Mean IQ	29.3	31.7	21.5	24.4	15.7	49.2	59.7
Mean ICAP Adaptive Behavior Score (in months)	53.5	55.5	36.4	43.4	23.1	104.8	136.6
Mean ICAP Service Level Score	45.3	47.6	35.5	45.7	33.1	66.9	77.3
Mean HRST	2.46	2.2	2.6	2.4	4.6	1.7	1.11
Presence of Psychiatric Diagnosis	47.6%	52.2 %	50.6%	42.7%	31.7%	45.5%	25%
Mean Length of Previous Stay at SODC in years	13.8	12.2	19.9	13.6	20.3	2.9	0.6

Those individuals transferring to another SODC did not significantly differ in age from those moving to a 24-CILA or ICF/DD, however were significantly older than those going to jail or family home and significantly younger than those moving into an SNF. There was no significant difference in HRST between those transitioned to another SODC and those transitioned to an ICF/DD. Individuals transitioning to another SODC had a significantly (p=.000) lower IQ as compared to the CILA, family home, and jail group, however, there was no difference between the SODC and ICF/DD or SNF groups with respect to IQ.

Those moving into an SNF were significantly older, had a lower IQ, had a higher health risk and had a significantly lower ICAP Adaptive Behavior and Service Level score than the other groups. This group had the second lowest occurrence of psychiatric diagnosis at 31.7%. This

group had a significantly longer previous stay at an SODC than the other groups with the exception of those transferring to another SODC.

Those going to jail and those moving in with family from the SODC were significantly younger, had a higher IQ, higher ICAP Behavioral and Service Level score, higher ICAP Service Level score, and shorter length of previous stay at an SODC as compared to all other groups, although there was no significant difference between these two groups with respect to length of stay. There was no significant difference between those going to jail and moving into a family home with respect to HRST. Those going to jail had the lowest incidence of psychiatric diagnosis as compared to the other groups.

Differences in IQ between groups were all statistically significant (p=.000) with the exception of between ICF/DD and SODC transition groups.

Table 12. Comparison of Characteristics of Those Returning to an SODC and Those Remaining in CILA Placement

	Remaining in CILA Placement (n = 338)	Returning to SODC after CILA Placement (n = 62)	Significance (p value)
Gender			
Male	62.4%	74.2%	$p = .076\ddagger$
Female	37.6%	25.8%	
Mean Age	47.48	40.95	p = .000§
Mean IQ	29.38	44.5	p = .000§
Mean ICAP Adaptive Behavior Score (in months)	51.06	72.25	p = .000§
Mean ICAP Service Level Score	45.81	53.7	p = .003§
HRST	2.12	2.11	p = .964§
Presence of Psychiatric Diagnosis	50.6%	71%	p=.003‡
Mean Length of Previous Stay at SODC in years	14.54	5.98	p = .000§
Provision of Technical Assistance	16.6%	38.7%	
Medical	1.8%	8.0%	p = .000‡
Behavioral	69.9%	83%	
Medical & behavioral	23%	8.0%	
Dietary	5%	0%	

[§]Based on an independent samples T-test ‡ Based on Chi Square test

When comparing those remaining in CILA placement and those returning to an SODC after CILA placement, the two groups significantly differ with regard to age, IQ, ICAP Adaptive Behavior and Service Level scores, and length of previous stay at SODC. There is no significant difference, however, with respect to health risk between the two groups. Those returning to an SODC were more likely to have a psychiatric diagnosis compared to their CILA counterparts. It must be noted that a total of 658 individuals transferred to a CILA from an SODC during the study period. The current status of 179 of the individuals that transferred to a CILA is undocumented at the SODC level, and therefore, this data does not reflect characteristics of those persons.

Of all persons transitioning to a CILA, 19.5% (n=128) received technical assistance. Of those individuals, 3.9% (n = 5) received TA for medical reasons, 78% (n = 100) received TA for behavioral reasons, 2.3% (n = 3) received TA for dietary issues, and 15.6% (n = 20) received TA for a combination of medical and behavioral issues. Of those that received TA after transitioning to a CILA from an SODC, 43.8% remained in their CILA placement, 18.8% of those that received it returned to an SODC and the remainder transitioned into another non-SODC setting.

Question 7: What are the characteristics of the individuals that have died since transition?

Of the 164 (11.1%) persons that have died since transitioning out of an SODC 60.4% (n = 99) were male and 39% (n = 64) were female with an average age of 55.5 years (sd=13.97) ranging from 17 to 92 years of age. The majority of these individuals (33.5%) transitioned out of Lincoln. The mean IQ was 17.2 (sd = 16.02, range 1-67), mean ICAP Adaptive Behavior Score in months was 26.2 (sd=29.9, range 3-147), mean ICAP Service Level Score was 32.7 (sd = 16.21, range 1-78), mean HRST was 3.87 (sd = 1.54, range 1-6), mean length of stay at SODC in years was 21.6 (sd = 16.55, range under one year to 77 years), and 38.4% had a psychiatric diagnosis.

Of the 164 individuals that died post-transition, 64 (39%) had moved to a Skilled Nursing Facility, 39 (23.8%) to a 24-CILA, 39 (23.8%) to an SODC, 13 (7.9%) to an ICF/DD, 4 (2.4%) to the home of a family member, one (0.6%) to an Intermittent CILA, and one (0.6%) out of

state. Two (1.2%) individual's transition placement information was missing. Of those individuals moving to a nursing home, the average age was 61 (sd = 15.3, ranging from 37 – 82); Health Risk Screening Tool level was 4.77 (sd = 1.33); ICAP Service Level score was 30.9 (sd = 14.6) and average length of stay at SODC was 21.62 years (sd = 16.55).

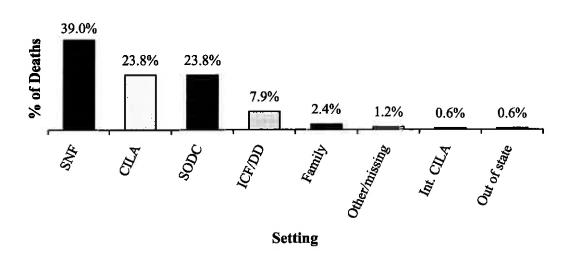


Figure 8. Post-transition Deaths by Placement Between 10/01/2001 and 6/30/2008

Of the 133 individuals that died while residing at an Illinois SODC during the study period, 79 (59.4%) were male while 54 (40.6%) were female, the mean age was 54.05 (sd=15.00, range 12-87), mean IQ was 17.11 (sd=16.84, range 1-72), Mean ICAP Adaptive Behavior Score in months was 22.93 (sd=22.99, range 1-141), mean ICAP Service Level Score was 32.18 (sd=16.15, range 1-74), mean HRST was 3.52 (sd=1.45, range 1-6), mean length of stay at SODC in years was 18.96 (sd=14.37, range under one year to 66 years), and 29% had a psychiatric diagnosis.

The only two variables for which there was a statistically significant difference were HRST scores and length of previous stay at an SODC. Those dying after transition out of an SODC had a longer length of previous stay (p=.048) at an SODC as well as had a higher health risk (p=.028).

Table 13. Comparison of Characteristics of Those Dying in an SODC and Those Dying
Post-SODC Transition in Any Placement
Between 10/01/2001 and 6/30/2008

Detwee	Between 10/01/2001 and 0/30/2008				
		Post-			
	SODC Deaths	Transition	Significance		
	(n = 133)	Deaths	(p) value)*		
	(/	(n = 164)	v ,		
Gender		()			
Male	59.4%	60.4%	$p = .575 \ddagger$		
2,232	40.6%	39.0%	p575		
Female	40.0%	39.0%			
Mean Age	54.05	55.46	p = .351§		
Mean IQ	17.11	17.20	p = .934§		
Mean ICAP Adaptive Behavior Score (in months)	22.96	26.22	p = .396§		
Mean ICAP Service Level Score	32.29	32.67	p = .978§		
HRST	3.52	3.87	p = .028§		
Presence of Psychiatric Diagnosis	28.6%	38.4%	p = .077‡		
Mean Length of Previous Stay at SODC in years	17.7	21.62	p = .048§		

[§]Based on an independent samples T-test

Characteristics of persons dying during the study period were examined with regard to the setting in which they died using a one-way analysis of variance (see Table 14). There was no significant difference between groups with respect to age, however HRST scores were significantly different between all groups (p=.000). With respect to ICAP Adaptive Behavior scores, the only significant difference was between those transitioning to a SNF and another SODC (p=.014). Persons moving to a 24-hour CILA had a significantly higher ICAP Service Level score than their counterparts transitioned to another SODC (p=.007). Additionally, those moving to another

[‡] Based on Chi Square test

SODC had a significantly expiring in an SODC and t		y at an SODC	as compared	to both those
	8			

Table 14. Comparison of Individual Characteristics of Those Dying Across Settings Between 10/01/2001 and 6/30/2008

		Deaths	Deaths	Deaths	Deaths	
	All Deaths	after	after	after	after	
	Occurring at	Transition	Transition	Transition	Transfer to	į.
	(n = 133)	(n = 65)	(n=39)	(n=13)	SODC (n=39)	Significance $(p \text{ value})$
Gender			,			\ \ \ \
Male	59.4%	67.7%	56.4%	54%	56.4	
Female	40.6%	32.3%	43.6%	39%	43.6	p = .575‡
Missing	%0	%0	%0	%0	%0	-
Mean Age	54.05	57.72	57.95	52.38	51.05	$p=.288\S$
Mean IQ	17.11	16.02	20.90	21.31	11.43	p=.027\$
Mean ICAP Adaptive Behavior Score (in months)	22.96	22.52	35.10	31.77	15.14	p = .001§
Mean ICAP Service Level Score	32.29	30.81	39.21	32.46	25.53	p = .001§
HRST	3.52	4.72	2.74	3.54	3.97	000. = d
Presence of Psychiatric Diagnosis	28.6%	33.8%	33.3%	61.5%	35.9%	<i>p</i> = .077‡
Mean Length of Previous Stay at SODC in years	17.7	20.97	20.56	14.31	28.03	p = .008§

‡ Based on Chi Square test

DISCUSSION

This study sought to answer the following seven questions, which have been discussed in detail throughout the report:

- 1. How many individuals transitioned out of Illinois SODCs since the initiation of the closure of the Lincoln Developmental Center on October 1, 2001?
- 2. What are the characteristics of those who transitioned out of SODCs in Illinois?
- 3. To what type of residential settings did individuals transfer?
- 4. To what extent did individuals remain in the residential setting to which they were transferred?
- 5. What are the characteristics of the persons who returned to an SODC after transition as compared to those who remained in their transition placement?
- 6. How do characteristics of persons that transitioned compare across residential settings?
- 7. What are the characteristics of the individuals who have died since transition during the reporting period?

Numerous studies have been completed examining deinstitutionalization outcomes for individuals focusing on movement from institutions to community-based settings (e.g., Kim, Larson, and Lakin, 1999; and Heller, Schindler & Rizzolo, 2008). Although similar studies have been conducted in Illinois to determine outcomes for individuals leaving SODCs (Braddock, Heller & Zashin, 1984; Heller, Factor & Braddock, 1986; Fujiura, Fitzsimons-Cova & Bruhn, 2002), prior to this project a study investigating transitions across all Illinois SODCs over an extended period of time has not been completed.

In addition to answering the seven initial study questions, six themes emerged from the data:

<u>Theme 1</u>: During periods of SODC closures, individuals living in SODCs were less likely to transfer to community settings.

The majority (51.4%) of individuals moved from an SODC into a community setting [24-hour Community Integrated Living Arrangements (CILA), intermittent CILA, or family home]. An additional 46.6% moved from the SODC into another congregate setting (another SODC, Skilled Nursing Facility (SNF), Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD), State Operated Mental Health Center (MHC), or jail). However, these amounts shift drastically when Lincoln Developmental Center transition data is removed. If Lincoln transfers are not considered, the percentage of individuals that transferred from an SODC to a community setting increases to 63.8% and the percentage of those transferring to other congregate settings decreases to 31%. This data suggest that transitions from SODCs to community placements were more likely to occur during non-closure periods.

This data supports results reported from past closure evaluations. Braddock, Heller and Zashin (1984) reported that nearly all (95%) of the 820 individuals residing at Dixon Developmental Center were transferred to another SODC during the course of its closure. In a subsequent evaluation of the Galesburg Mental Health Center closure, Heller, Factor, and Braddock (1986) found that of the 331 individuals with developmental disabilities residing at Galesburg, 67% (n=222) transferred to other SODCs at the time of its closure.

Data from the present study indicate that 78% of individuals transitioning as a result of the Lincoln closure transferred to other SODCs while 13% moved into community-based settings. Lincoln transfers to other SODCs account for 85% of all SODC transfers occurring during the study period. If Lincoln SODC transfers are not considered, the percentage of individuals transferred to other SODCs during the study period decreases to 3.2%. It appears this data would indicate that individuals were less likely to transfer into community-based living arrangements during an SODC closure as compared to non-closure related transfers. Based on this information, it is recommended that the recent closure of Howe Developmental Center be evaluated in terms of categorical transition placement (community-

based, other congregate care setting, or other SODC) to detect and examine trends toward reliance on congregate care facilities during SODC closure.

Theme 2: The majority (39%) of post-transition deaths occurred in Skilled Nursing Facilities.

There was a total of 297 deaths within the study period, of which 133 (45%) died while in an SODC and 164 (55%) died post-transition. The majority of post-transition deaths occurred in Skilled Nursing Facilities (48%, n=64) among a population with a higher health risk. Of this group, the majority (33.5%) had moved from Lincoln and had an average length of stay in an SODC of nearly 22 years, ranging from under one year to 77 years.

It is important to keep in mind that this data does not provide the cause or the circumstances surrounding individual deaths. For this reason, it is wise to heed Fujiura's warning regarding the institution-community dichotomy in which he notes that placement *setting* is not a cause of death, that there are "a host of other factors act[ing] as agents of mortality risk" (p. 401, 1998). Collection and analysis of not only mortality data, but health, health care quality and access across all settings would be key to understanding health risk in Illinois' long term care settings for individuals with developmental disabilities.

<u>Theme 3</u>: As evidenced by the absence of transition data at the SODC level, the utility of post-transition outcome data could be strengthened through sharing and coordination at varying Department levels.

The current status for individuals was undocumented at the SODC level in 19.9% of cases (n = 295). Although the Division of Developmental Disabilities administration has access to the data at the DHS central office, consideration should be given to revision of post-transition outcome documentation data available at the SODC level. SODC access to such outcome data would allow the examination of trends on an on-going basis and inform future transition processes at the facility, Pre-Admission Screening agency and community-based residential provider levels.

<u>Theme 4</u>: The most frequent reason for return to SODCs across all centers was due to behavioral issues, warranting analysis of the type, severity and duration of the particular behaviors contributing to return as well as examination of the accessibility, delivery, and effectiveness of related community-based behavioral supports in Illinois.

Similar to past studies (see, for example, Beadle-Brown, Mansell & Kozma, 2007), the majority (72.7%) of the individuals in the present study that returned to an SODC after transition, did so due to behavioral reasons, while 9.7% did so due to medical reasons, 5.8% due to "other" reasons, and this information was unknown for the remaining 11.7% (see figure 6). This data suggest that it would be beneficial to investigate the type, severity and duration of the particular behaviors contributing to return as well as examination of the accessibility, delivery, and effectiveness of related community-based behavioral supports in Illinois. Such exploration may shed light on successful behavioral supports for individuals transitioning out of SODCs and thereby improve the number of successful community transitions for people with challenging behaviors.

<u>Theme 5</u>: Individuals who were transferred to jail settings had a high likelihood of failed community placement after release from jail, suggesting that existing community-based supports may not be adequate for this population.

The cohort of individuals being transferred to jails were all males, were younger, had higher IQ scores, higher ICAP scores, shorter lengths of stay at the SODC, lower health risk, and lower incidence of mental illness than the rest of the sample. In addition, these individuals returned to the SODC at a rate of 30% after release from jail, as opposed to the overall rate of 10.4%. This suggests that for younger, healthier, more independent men with mild-moderate intellectual disability, existing less than 24-hour community-based supports may not be adequate. It appears that examination of accessibility of services and supports for individuals with these characteristics are warranted. In addition, further examination of factors leading up to jail placement for these individuals is critical.

<u>Theme 6</u>: Only 28% of individuals returning to an SODC post-transition received documented technical assistance, warranting further analysis to inform future transition policy.

Of all individuals transitioning out of an SODC, 12.8% received TA. Only 27.9% of individuals who returned to SODCs post-transition received documented technical assistance,

of which 51% returned from community settings. Of the individuals who transitioned to CILA placements, those receiving documented technical assistance were able to remain in the placement 43.8% of the time, 18.8% returned to an SODC despite receipt of TA, and the remainder transferred to a non-SODC setting. Examination of access, delivery, and effectiveness of technical assistance for individuals leaving SODCs is recommended to determine both strengths and areas needing improvement in the SODC transition process in order to inform future transition policy.

APPENDIX A: Sample Characteristics

Table 15. Comparison of Characteristics of all Individuals Transitioned Between 10/01/2001 and 6/30/2008

	Overall (n = 1613)	Choate	\mathbf{Fox} $(n = 44)$	Howe (n = 235)	Howe Jacksonville Kiley $(n = 235)$ $(n = 147)$ $(n = 10)$	Kiley $(n = 105)$	Lincoln (n= 370)	Ludeman	Mabley	Murray	Shapiro
	(CTOT – 11)	(0C7 - II)	‡ !	(CC7 - II)	(/+1 – 11)	(col – n)	(n/c - 11)	(m- 102)	(m = m3)	(/11 = 11)	(007-11)
Mean Age	47.4	39.3	41.8	50.4	48	51.1	48.9	46.3	45.7	44.7	54.3
Mean IQ	34.7	49.9	3.5	27.6	33.3	29.6	18	23.9	23.7	23.2	26.8
Mean ICAP Adaptive Behavior Score (in months)	50.9	9.86	9.0	46.8	57	49.2	32.6	41.3	41.0	31.5	50.70
Mean ICAP Service Level Score	44.2	64.3	24.3	43.7	47.3	44.1	34.1	41.1	37.7	35.5	47.3
Mean HRST	2.55	1.59	4.05	2.52	2.66	2.82	2.70	2.23	2.11	2.26	3.66
Presence of Psychiatric Diagnosis	46.1%	41.9%	22.7%	43.4%	56.4%	49.5%	47.0%	33.9%	47.6%	52.1%	51.8%
Mean Length of Previous Stay at SODC in years	14.1	7.9	12.2	11.5	10.0	15.5	22.3	16.2	14.2	13.4	17.0

APPENDIX B: Choate

Table 16. Demographics of Individuals Transitioned Out of Choate Between 10/01/2001 and 6/30/2008

(n = 258)

	#	%	Overall % (n = 1,613)
Gender			
Male	217	84.1%	66.2%
Female	41	15.9%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	108	41.9%	46.1%
No	150	58.1%	53.9%
Level of ID			
Mild	146	56.6%	19.3%
Moderate	54	20.9%	15.6%
Severe	20	7.8%	16.3%
Profound	25	9.7%	46.9%
N/A	9	1.6%	1.2%
Not specified	4	1.6%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	250	96.5%	93.3%
Yes	8	3.2%	6.7%
Autism	3	37.5%	65.7%
PDD, NOS	5	62.5%	36.1%
Guardianship status			
Legally competent	132	51.2%	10.2%
Private guardian – family member	65	25.2%	46.9%
Private guardian – non family member	12	4.7%	2.2%
Public Guardian	49	19%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 9. Choate Transitions by Setting Between 10/01/2001 and 6/30/2008 (n =258)

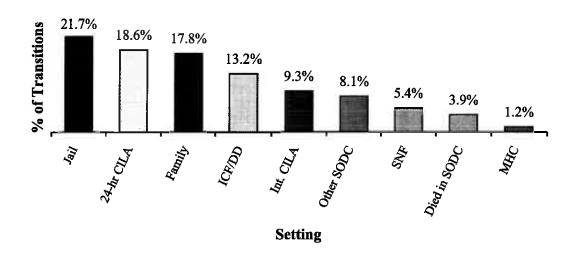


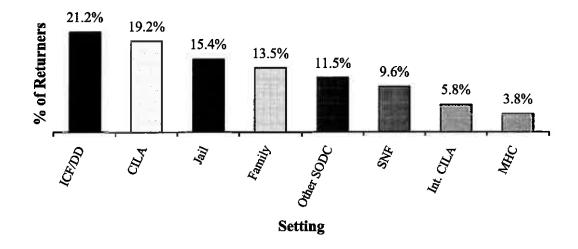
Table 17. Status of Individuals Transitioned from Choate as of June 30, 2008

(n = 248, does not include 10 individuals who died while residing at Choate)

Placement	#	%
Continuous placement (remained with transition provider)	138	55.6
Unknown	51	20.6
Deceased	5	2.0
Returned to SODC	52	21
Different residence, different provider (non-SODC)	2	.8
Same provider, different residence	0	0
State Operated Mental Health Center	0	0
Total	248	

Of those 52 individuals returning to an SODC placement post-transition (20.2% of the sample), 51 (98.1%) returned due to behavioral issues. Technical assistance was documented for nine (3.5%) of those transitioned. Five (56%) individuals received behavioral technical assistance and four (44%) received dietary technical assistance. Documentation of the provision of technical assistance was absent for the individuals that returned to an SODC placement post-transition.

Figure 10. Persons Transitioned from Choate and Returning to SODC Placement Between 10/01/2001 and 6/30/2008 by Transition Setting (n = 52)



APPENDIX C: Fox

Table 18. Demographics of Individuals Transitioned from Fox Between 10/01/2001 and 6/30/2008

(n = 44)

	#	%	Overall % (n = 1,613)
Gender			
Male	31	70.5%	66.2%
Female	13	29.5%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	10	22.7%	46.1%
No	34	77.3%	53.9%
Level of ID			
Mild	1	2.3%	19.3%
Moderate	3	6.8%	15.6%
Severe	6	13.6%	16.3%
Profound	34	77.3%	46.9%
N/A	0	0%	1.2%
Not specified	0	0%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			93.3%
No	41	6.7%	93.3
Yes	3	65.7%	6.7
Autism	3	36.1%	65.7
PDD, NOS	0		36.1
Guardianship status			
Legally competent	4	9.1%	10.2%
Private guardian – family member	23	52.3%	46.9%
Private guardian – non family member	1	2.3%	2.2%
Public Guardian	16	36.4%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 11. Fox Transitions by Setting Between 10/01/2001 and 6/30/2008 (n = 44)

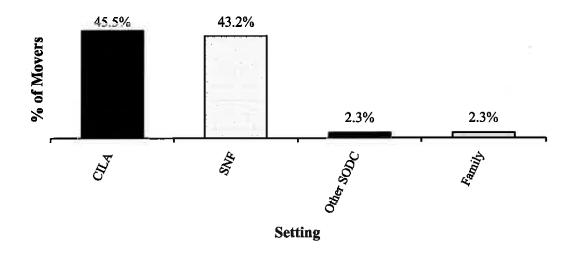


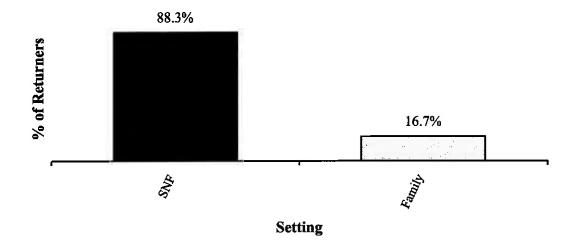
Table 19. Status of Individuals Transitioned from Fox as of June 30, 2008 (n = 44)

Placement	#.	%
Continuous placement (remained with transition provider)	7	15.9%
Unknown	18	40.9%
Deceased	13	29.5%
Returned to SODC	6	13.6%
Different residence, different provider (non-SODC)	0	0%
Same provider, different residence	0	0%
State Operated Mental Health Center	0	0%
Total	44	100.0%

Technical assistance was provided to 43 (97.7%) of those transitioned. Nineteen (43.2%) individuals received medical technical assistance and 14 (31.8%) received behavioral technical assistance. Ten (22.7%) received technical assistance for both medical and behavioral issues. Of those six individuals returning to an SODC placement post-transition (13.6% of those transitioned), 100% returned due to issues listed as "other". All six of the individuals that returned to an SODC placement post-transition received technical assistance for medical issues.

Figure 12. Persons Transitioned from Fox and Returning to SODC Placement by Setting Between 10/01/2001 and 6/30/2008

(n=6)



APPENDIX D: Howe

Table 20. Demographics of those Transitioned from Howe Between 10/01/2001 and 6/30/2008

(n = 235)

	#	0/0	Overall % (n = 1,613)
Gender			(H 1,015)
Male	144	61.3	66.2%
Female	91	38.7	33.5%
Missing	0	0	0.2%
Psychiatric Diagnosis			
Yes	102	43.4	46.1%
No	133	56.6	53.9%
Level of ID			
Mild	38	16.2	19.3%
Moderate	46	19.6	15.6%
Severe	36	15.3	16.3%
Profound	112	47.7	46.9%
N/A	3	1.3	1.2%
Not specified	0	0	0.6%
Missing	0	0	0.1%
ASD Diagnosis			
No	214	91.1	93.3%
Yes	21	8.9	6.7%
Autism	17	81%	65.7%
PDD, NOS	4	19%	1.9%
Guardianship status			
Legally competent	7	3%	10.2%
Private guardian – family member	150	63.8%	46.9%
Private guardian – non family member	12	5.1%	2.2%
Public Guardian	66	28.1%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 13. Howe Transitions by Setting Between 10/01/2001 and 6/30/2008 (n = 235)

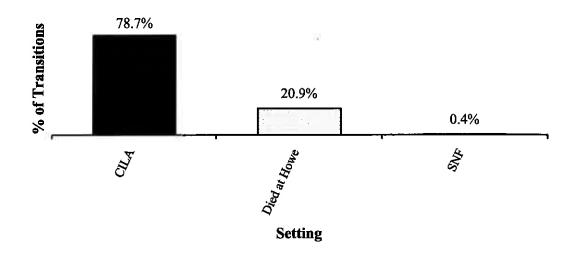


Table 21. Status of Individuals Transitioned from Howe as of June 30, 2008

(n = 186, not including 49 individuals that died while residing at Howe)

Placement	#	<u>%</u>
Continuous placement (remained with transition provider)	39	21%
Unknown	116	62%
Deceased	18	9.7%
Returned to SODC	13	7%
Different residence, different provider (non-SODC)	0	0%
Same provider, different residence	0	0%
State Operated Mental Health Center	0 =	0%
Total	186	100%

Technical assistance was provided to one individual (0.5%) post-transition and was behavioral in nature. All of the 13 (100%) individuals returning to an SODC placement post-transition from Howe had been placed in a CILA program. Of the 13, 11 (85%) returned due to behavioral issues, while one (7.7%) returned for "other" reasons and for one individual the reason for return is missing/unknown. None of the individuals that returned to an SODC post-transition received technical assistance.

APPENDIX E: Jacksonville

Table 22. Demographics of Individuals Transitioned from Jacksonville Between 10/01/2001 and 6/30/2008

(n = 147)

	#	%	Overall % (n = 1,613)
Gender			
Male	111	75.5%	66.2%
Female	36	24.5%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	83	56.5%	46.1%
No	64	43.5%	53.9%
Level of ID			
Mild	45	30.6%	19.3%
Moderate	23	15.6%	15.6%
Severe	29	19.7%	16.3%
Profound	49	33.3%	46.9%
N/A	1	0.7%	1.2%
Not specified	0	0%	0.6%
Missing	0	0	0.1%
ASD Diagnosis			
No	136	92.5%	93.3%
Yes	11	7.5%	6.7%
Autism	8	72.7%	65.7%
PDD, NOS	3	27.3%	36.1%
Guardianship status			
Legally competent	5	3.4%	10.2%
Private guardian – family member	77	52.4%	46.9%
Private guardian – non family member	4	2.7%	2.2%
Public Guardian	60	40.8%	28.8%
Unknown/not listed	1	0.7%	11.9%

Figure 14. Jacksonville Transitions by Setting Between 10/01/2001 and 6/30/2008(n = 147)

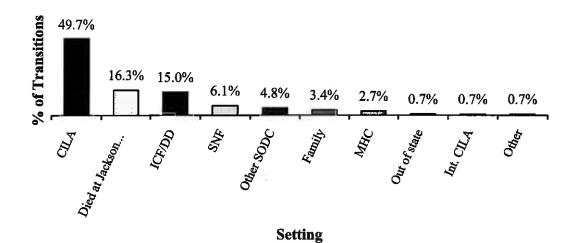


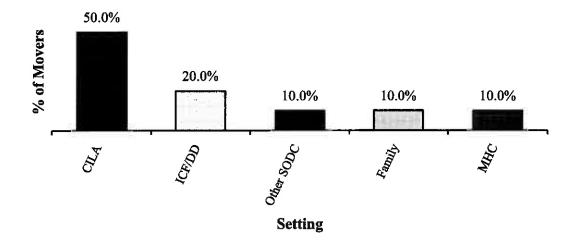
Table 23. Status of Individuals Transitioned from Jacksonville as of June 30, 2008

(n = 123, does not include the 24 who died at Jacksonville)

Placement	#	%
Continuous placement (remained with transition provider)	59	48
Unknown	26	21.1
Deceased	14	12.2
Returned to SODC	10	8.1%
Different residence, different provider (non-SODC)	4	3.3
Same provider, different residence	9	7.3
State Operated Mental Health Center	1	0.8
Total	123	100.0

Of those 10 (8.1%) individuals returning to an SODC placement post-transition, 9 (90%) returned due to behavioral issues and the remaining individual (10%) returned for "other" reasons. Technical assistance was provided to 44 (29.9%) of those transitioned. Forty-two (97.7%) individuals received behavioral technical assistance and one (2.3%) received medical and behavioral technical assistance. Nine (90%) of the individuals that returned to an SODC placement post-transition from Jacksonville received technical assistance. Eight (88.9%) received technical assistance for behavioral issues and one (11.1%) received technical assistance for both medical and behavioral issues.

Figure 15. Persons Transitioned from Jacksonville and Returning to SODC Placement Between 10/01/2001 and 6/30/2008 by Setting (n = 10)



APPENDIX F: Kiley

Table 24. Demographics of Individuals Transitioned From Kiley Between 10/01/2001 and 6/30/2008

(n = 105)

	#	%	Overall % (n = 1,613)
Gender			(11,010)
Male	59	56.2	66.2
Female	46	43.8	33.5
Missing	0	0	0.2
Psychiatric Diagnosis			
Yes	52	49.5%	46.1%
No	53	50.5%	53.9%
Level of ID			
Mild	10	9.5%	19.3%
Moderate	16	15.2%	15.6%
Severe	21	20.0%	16.3%
Profound	57	54.3%	46.9%
N/A	1	1.0%	1.2%
Not specified	0	0%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	105	100%	93.3%
Yes	0	0%	6.7%
Autism	0	0%	65.7%
PDD, NOS	0	0%	36.1%
Guardianship status			
Legally competent	5	4.8%	10.2%
Private guardian – family member	85	81.0%	46.9%
Private guardian – non family member	1	1.0%	2.2%
Public Guardian	14	13.3%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 16. Kiley Transitions by Setting Between 10/01/2001 and 6/30/2008(n = 105)

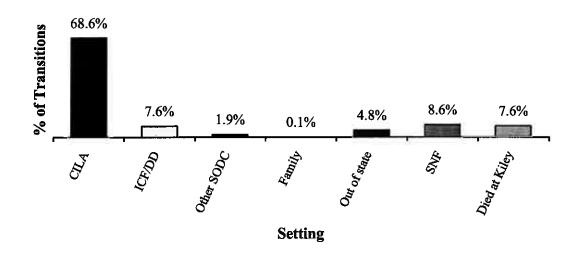


Table 25. Status of Individuals Transitioned From Kiley as of June 30, 2008

(n = 97, does not include 8 individuals who died at Kiley)

Placement	#	<u>%</u>
Continuous placement (remained with transition provider)	64	66
Unknown	1	1
Deceased	15	15.5
Returned to SODC	6	6.2
Different residence, different provider (non-SODC)	5	5.2
Same provider, different residence	6	6.2
State Operated Mental Health Center	0	0
Total	97	100.0

Technical assistance was provided to 38 (36.2%) of those transitioned, of which five (13.2%) received medical technical assistance, 24 (63.2%) received behavioral technical assistance, and nine (23.7%) received both medical and behavioral technical assistance. Of the six (6.2%) individuals returning to an SODC placement post-transition from Kiley, four (66.6%) returned due to behavioral issues, and two (33.3%) returned for medical issues. All six individuals (100%) returning to an SODC had been transitioned into CILA placement.

APPENDIX G: Lincoln

Table 26. Demographics of Individuals Transitioned From Lincoln Between 10/01/2001 and 6/30/2008

(n = 370)

	#	%	Overall % (n = 1,613)
Gender			, ,
Male	231	62.4%	66.2%
Female	135	36.5%	33.5%
Missing	4	1.1%	.0.2%
Psychiatric Diagnosis			
Yes	174	47.0%	46.1%
No	196	53.0%	53.9%
Level of ID			
Mild	11	3.0%	19.3%
Moderate	51	13.8%	15.6%
Severe	82	22.2%	16.3%
Profound	224	60.5%	46.9%
N/A	1	0.3%	1.2%
Not specified	1	0.3%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	340	91.9%	93.3%
Yes	30	8.8%	6.7%
Autism	22	73.3%	65.7%
PDD, NOS	8	26.7%	36.1%
Guardianship status			
Legally competent	4	1.1%	10.2%
Private guardian – family member	120	32.4%	46.9%
Private guardian – non family member	0	0%	2.2%
Public Guardian	56	15.1%	28.8%
Unknown/not listed	190	51.4%	11.9%

Figure 17. Lincoln Transitions by Setting Between 10/01/2001 and 6/30/2008(n = 370)

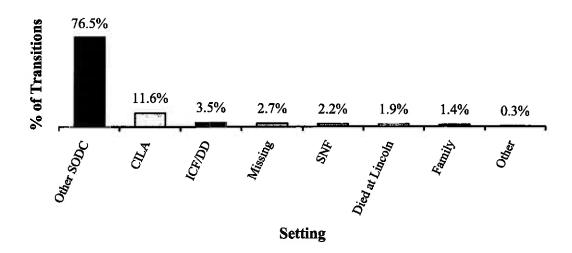


Figure 18. Lincoln Transitions by Receiving SODC Between 10/01/2001 and 6/30/2008

(in real numbers, n = 285)

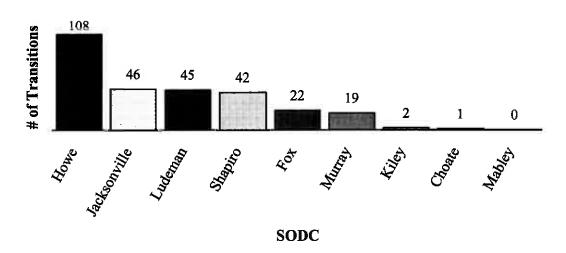


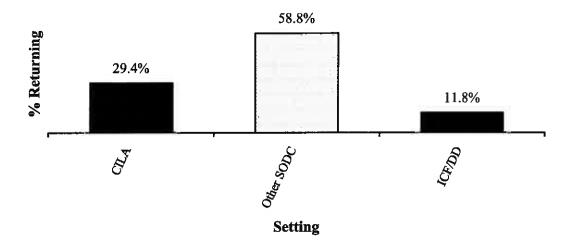
Table 27. Status of Individuals Transitioned From Lincoln Between 10/01/2001 and 6/30/2008

(n = 363, does not include 7 individuals who died at Lincoln)

Placement	#	%
Continuous placement (remained with transition provider)	217	59.8
Missing/Unknown	2	0.6
Deceased	55	15.2
Transferred to SODC	17	4.7
Different residence, different provider (non-SODC)	72	19.8
Same provider, different residence	0	0
State Operated Mental Health Center	0	0
Total	363	100.0

Of the 17 individuals with current status listed as returning to an SODC placement as of June 30, 2008, the reason for return is unknown and there is no information available on receipt of technical assistance. Five individuals (29.4%) returned from CILA placements, and two (11.8%), from an ICF/DD and the remaining 10 (58.8%) were listed as returning to an SODC, however, it is unknown if this means that these individuals were transferred to another SODC from Lincoln, or if they were placed in an SODC and then relocated to another setting before returning to an SODC.

Figure 19. Persons Transitioned from Lincoln and Returning to an SODC Between 10/01/2001 and 6/30/2008 by Setting (n=17)



APPENDIX H: Ludeman

Table 28. Demographics of Individuals Transitioned From Ludeman Between 10/01/2001 and 6/30/2008 (n = 109)

	#	%	Overall % (n = 1,613)
Gender			, ,
Male	71	65.1%	66.2%
Female	38	34.9%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	37	33.9%	46.1%
No	72	66.1%	53.9%
Level of ID			
Mild	11	10.1%	19.3%
Moderate	13	11.9%	15.6%
Severe	20	18.3%	16.3%
Profound	65	59.6%	46.9%
N/A	0	0%	1.2%
Not specified	0	0%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	104	95.4%	93.3%
Yes	5	4.6%	6.7%
Autism	4	80%	65.7%
PDD, NOS	1	20%	36.1%
Guardianship status			
Legally competent	1	0.9%	10.2%
Private guardian family member	40	36.7%	46.9%
Private guardian – non family member	3	2.8%	2.2%
Public Guardian	65	59.6%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 20. Ludeman Transitions by Setting Between 10/01/2001 and 6/30/2008 (n = 109)

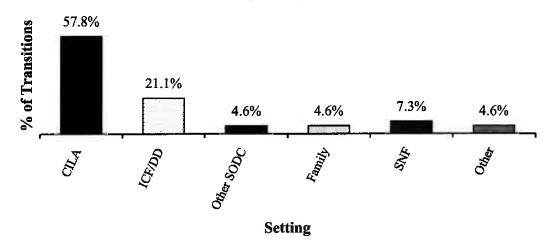
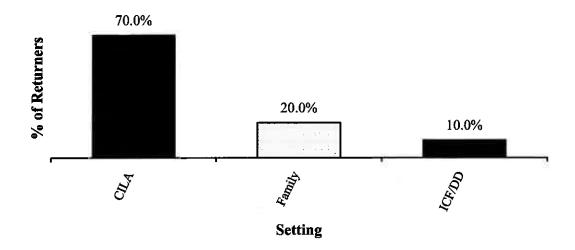


Table 29. Status of Individuals Transitioned From Ludeman as of June 30, 2008 (n = 109)

Placement	#	%
Continuous placement (remained with transition provider)	80	73.4
Missing/Unknown	0	0
Deceased	16	14.7
Returned to SODC	10	9.2
Different residence, different provider (non-SODC)	2	1.8
Same provider, different residence	1	.9
State Operated Mental Health Center	0	0
Total	109	100.0

Technical assistance was provided to eight (7.3%) of those transitioned, of which 100% was technical assistance for behavioral issues. Five (56%) individuals received behavioral technical assistance and four (44%) received dietary technical assistance. None of the individuals that returned to an SODC placement post-transition, however, received technical assistance. Of those 10 (9.2%) individuals returning to an SODC placement post-transition all ten (100%) returned due to behavioral issues. Of those 10, three (30%) received technical assistance all for behavioral issues.

Figure 21. Persons Transitioned from Ludeman and Returning to SODC Placement Between 10/01/2001 and 6/30/2008 by Setting (n = 10)



APPENDIX I: Mabley

Table 30. Demographics of Individuals Transitioned From Mabley Between 10/01/2001 and 6/30/2008

(n = 63)

	#	%	Overall % (n = 1,613)
Gender			
Male	40	63.5%	66.2%
Female	23	36.5%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	30	47.6%	46.1%
No	33	52.4%	53.9%
Level of ID			
Mild	4	6.3%	19.3%
Moderate	6	9.5%	15.6%
Severe	10	15.9%	16.3%
Profound	36	57.1%	46.9%
N/A	2	3.2%	1.2%
Not specified	5	7.9%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	45	71.4%	93.3%
Yes	18	28.6%	6.7%
Autism	9	50%	65.7%
PDD, NOS	9	50%	36.1%
Guardianship status			
Legally competent	5	7.9%	10.2%
Private guardian – family member	44	69.8%	46.9%
Private guardian – non family member	1	1.6%	2.2%
Public Guardian	12	19.0%	28.8%
Unknown/not listed	1	1.6%	11.9%

Figure 22. Mabley Transitions by Setting Between 10/01/2001 and 6/30/2008(n = 63)

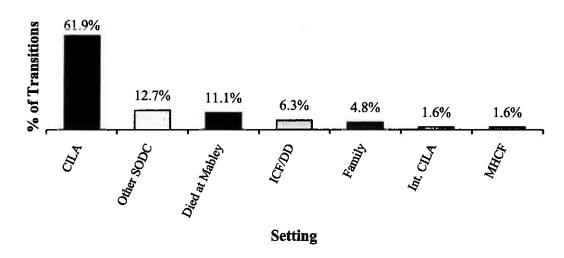


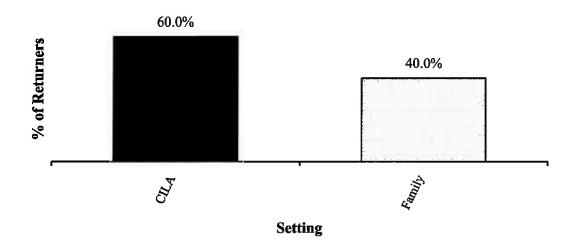
Table 31. Status of Individuals Transitioned From Mabley as of June 30, 2008

(n = 56, does not include 7 individuals that died at Mabley)

Placement	#	%
Continuous placement (remained with transition provider)	28	50
Whereabouts Missing/Unknown	21	37.5
Deceased	0	0
Returned to SODC	5	8.9
Different residence, different provider (non-SODC)	1	1.8
Same provider, different residence	1	1.8
State Operated Mental Health Center	0	0
Total	56	100.0

Technical assistance was provided to six (9.5%) of those transitioned, of which 100% was technical assistance for behavioral issues. Of the five (8.9%) individuals returning to an SODC placement post-transition, all five (100%) returned due to behavioral issues. Of the five individuals returning to an SODC, two (40%) received technical assistance for behavioral issues.

Figure 23. Persons Transitioned from Mabley and Returning to SODC Placement Between 10/01/2001 and 6/30/2008 by Setting (n = 5)



APPENDIX J: Murray

Table 32. Demographics of Individuals Transitioned From Murray Between 10/01/2001 and 6/30/2008

(n = 117)

	#	%	Overall % (n = 1,613)
Gender			
Male	61	52.1%	66.2%
Female	56	47.9%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	61	52.1%	46.1%
No	56	47.9%	53.9%
Level of ID			
Mild	20	17.1%	19.3%
Moderate	9	7.7%	15.6%
Severe	10	8.5%	16.3%
Profound	77	65.8%	46.9%
N/A	0	0%	1.2%
Not specified	1	0.9%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	113	96.6%	93.3%
Yes	4	3.4%	6.7%
Autism	4	100%	65.7%
PDD, NOS	0	0%	36.1%
Guardianship status			
Legally competent	2	1.7%	10.2%
Private guardian – family member	63	53.8%	46.9%
Private guardian – non family member	2	1.7%	2.2%
Public Guardian	50	42.7%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 24. Murray Transitions by Setting Between 10/01/2001 and 6/30/2008

(n = 117)

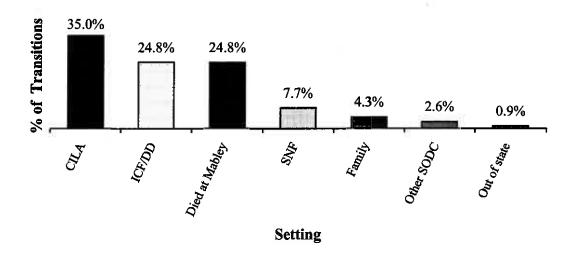


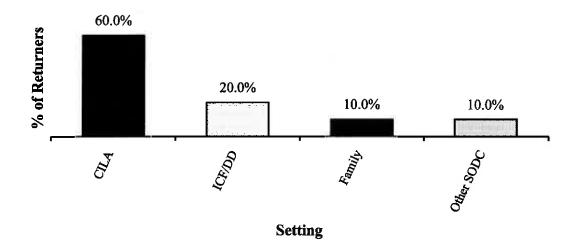
Table 33. Status of Individuals Transitioned From Murray as of June 30, 2008

(n =88, does not include 29 individuals that died at Murray)

Placement	#	%
Continuous placement (remained with transition provider)	64	72.7
Whereabouts Missing/Unknown	1	1.1
Deceased	7	7.95
Returned to SODC	10	12.5
Different residence, different provider (non-SODC)	2	2.3
Same provider, different residence	4	4.5
State Operated Mental Health Center	0	0
Total	88	

Technical assistance was provided to 13 (14.8%) of those transitioned. All 13 individuals received behavioral technical assistance. Of the 10 individuals returning to an SODC placement post-transition, all 10 returned due to behavioral issues. Eight of the individuals that returned to an SODC placement post-transition received technical assistance, all of which was for behavioral issues.

Figure 25. Persons Transitioned from Murray and Returning to SODC Placement Between 10/01/2001 and 6/30/2008 by Setting (n=10)



APPENDIX K: Shapiro

Table 34. Demographics of Individuals Transitioned From Shapiro Between 10/01/2001 and 6/30/2008

(n = 166)

	#	0/0	Overall % (n = 1,613)
Gender			
Male	104	62.7%	66.2%
Female	62	37.3%	33.5%
Missing	0	0%	0.2%
Psychiatric Diagnosis			
Yes	86	51.8%	46.1%
No	80	48.2%	53.9%
Level of ID			
Mild	26	15.7%	19.3%
Moderate	30	18.1%	15.6%
Severe	30	18.1%	16.3%
Profound	78	47.0%	46.9%
N/A	2	1.2%	1.2%
Not specified	0	0%	0.6%
Missing	0	0%	0.1%
ASD Diagnosis			
No	158	95.2%	93.3%
Yes	8	4.8%	6.7%
Autism	0	0%	65.7%
PDD, NOS	8	100%	36.1%
Guardianship status			
Legally competent	0	0%	10.2%
Private guardian – family member	90	54.2%	46.9%
Private guardian – non family member	0	0%	2.2%
Public Guardian	76	45.8%	28.8%
Unknown/not listed	0	0%	11.9%

Figure 26. Shapiro Transitions by Setting Between 10/01/2001 and 6/30/2008(n = 166)

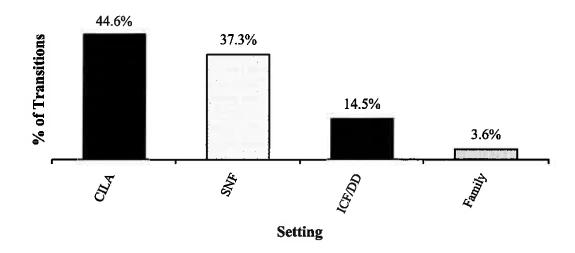
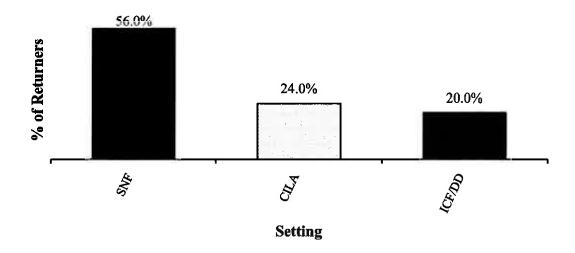


Table 35. Status of Individuals Transitioned From Shapiro as of June 30, 2008 (n=166)

Placement	#	%
Continuous placement (remained with transition provider)	50	30.1
Whereabouts Missing/Unknown	61	36.7
Deceased	21	12.7
Returned to SODC	25	15.1
Different residence, different provider (non-SODC)	5	3.0
Same provider, different residence	4	2.4
State Operated Mental Health Center	0	0
Total	166	

Technical assistance was provided to 28 (16.9%) of those transitioned. Twenty-four (14.5%) individuals received behavioral technical assistance, two (1.2%) received medical technical assistance, and two (1.2%) received a combination of medical and technical assistance. Of the 25 (15.1%) individuals returning to an SODC placement post-transition, 12 (7.2%) returned due to behavioral issues, and 13 (7.8%) returned for medical reasons. Eight (32%) of the individuals that returned to an SODC placement post-transition received technical assistance; 6 (75%) for behavioral issues and two (25%) for medical issues.

Figure 27. Persons Transitioned from Shapiro and Returning to SODC Placement Between 10/01/2001 and 6/30/2008 by Setting (n = 25)



APPENDIX L

List information for all persons leaving an Illinois SODC for another type of residence since October 1, 2001

	Technical Asist		
	Current Status		
	Guardian type		
to	Type of residence		
	D/C to (name of provider)		
Time Period of this Report	Medical Psychiatric Diagnoses at time of discharge		
: Period	бі		
Time	ICAP Service Level Score		
ameof	ICAP Adaptive Behavior Score		
	ТЅЯН		
	Discharge Date		
	himbA Date		
SODC Name Page of	DHS ID		

Instructions

DHS ID - use 9 digit DHS ID to identify each person who left the SODC; include all persons leaving for any reason. If a person had multiple discharges during the period, list each separately.

DOB – list only month and year of birth

Admit Date - date of admission to SODC for the current stay.

Discharged Date - date of discharge to other type of provider.

HRST at time of d/c - include the Health Risk Screening Tool level at the time of the discharge.

ICAP Adaptive Behavior Score at time of d/c - in months

ICAP Service Level at time of d/c - service level score, not service level

IO - indicate IO score at time of discharge

Medical/Psychiatric Diagnoses at time of Discharge - list all relevant medical and psychiatric diagnoses (including level of mental retardation) at time of discharge

D/C to (Name) - include name of provider who assumed responsibility upon discharge. If person died while living at the SODC, list "death" in this column. If they moved in to a family home, list "family".

Type of Residence - In column A, use the following codes to specify type of residence; in column B, list the maximum capacity if known

- 1 = 24 hour CILA
- 2 = intermittent CILA
- 3 = ICF/DD
- 4 = other Illinois SODC
- 5 = Illinois state-operated mental health hospital
- 6 =with family member
- 7 = out of state
- 8 = skilled nursing facility
- 9 = other
- 10 = n/a died in facility
- 11 = jail

Guardian type - use the following codes

- 1 = person is legally competent
- 2 = Office of the State Guardian
- 3 = private guardian (family member)
- 4 = private guardian (non-family member)
- 5 = unknown

Current Status: use the following codes

- 1 = continuous placement in the residence to which the person was discharged
- 2 = has moved to a different residence with the same provider
- 3 = has moved to a different residence with a different provider (non SODC)
- 4 =returned to an SODC
- 5 = individual is no longer living
- 6 = unknown
- 7 = State Operated Mental Health Center

If the current status is 4, list reason for return:

- 1 = medical reason(s)
- 2 = behavioral reason(s)
- 3 = n/a the persons did not return to an SODC
- 4 = other

Technical Assist - whether or not technical assistance has been provided following discharge

- 1 = Yes
- 2 =No to indicate.

If "yes," also indicate reason:

- 1 = medical
- 2 = behavioral
- 3 = n/a technical assistance was not provided
- 4 = dietary
- 5 = medical and behavioral
- 6 = Direct Linkage Aftercare

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